

CHAPTER 7

Taking Care of Myself and My Family



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You are doing a very hard job and you need to take care of yourself.

How can I stay healthy and get the support I need?

Anyone who cares for a child with a life-long health condition will feel tired, frustrated, fearful, or lonely from time to time. Just think of all you do. You manage your child's medicines, doctor visits, special diets, and other needs while caring for the rest of your family. You may also manage the grocery shopping, cooking, laundry, cleaning, and money. You can probably add more to your list, as well. But taking care of yourself is important, too. By taking care of yourself, you will be able to better care for your family.

Ideas to help you stay healthy

10

Mom's
Doctor Visit
9:30 am

- Be sure to make doctor and dentist visits for yourself, and go to them.
- Go for a walk, work out with an exercise show on TV, or do some other kind of exercise at least once a week.

Sun	Mon	Tue	Wed	Thu	Fri	Sat
1	2	3	4	5	6	7
8	9	10 Mom's Doctor Visit 9:30 am	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	31				

- Try to get enough sleep.
- Watch for signs of stress. Call your doctor, **social worker**, or **mental health professional** if you:
 - feel tired all the time.
 - feel like you want to be left alone.
 - feel hopeless or helpless.
 - cry a lot.
 - get moody or angry easily.
 - have trouble getting to sleep or staying asleep.
 - have trouble concentrating.
 - need drugs or alcohol to get through the day.

(See **About Mental Health**, What is mental health and why is it important? page 6–2.)

- When people ask if they can help, say, “Yes.” Let them know what you need, like prepare a meal, do the laundry, or watch the children. You may also ask them to call you in a few days to see how things are going.
- Try to learn as much as you can about **HIV** and **AIDS**. Talk to people who know about HIV, such as your child’s doctor, nurse, or case manager. Ask for information they may have, such as booklets, brochures, and videotapes. The more you know, the easier it will be to ask questions and talk with doctors and other providers about your child’s treatment.
- Get support from other caregivers. It helps to know you are not alone. If you can, join a support group.

When friends and family members ask if you need help, let them know what they can do.

Ask your case manager about HIV support groups in your area.

Are there HIV support groups for children and caregivers?

Support groups are very important for families dealing with **HIV**. These groups give children and adults a safe place to talk about their experiences and concerns. Support groups give people a chance to talk about their feelings, problem-solve, share child care, and get to know people who have the same kind of issues. Sharing ideas and information can be very useful to caregivers.

Support groups for children with **HIV**, or for their brothers and sisters, help children get to know each other and talk about their feelings. The children also learn about HIV and how to live with a life-long health condition. Ask your **case manager** about HIV support groups in your area.

How do I find time for my child with HIV and the rest of my family?

Any family with a child who has a life-long health condition faces many challenges. You must make sure your child with **HIV** gets medical care and support. At the same time, everyone else in the family has needs too. Meeting everyone's needs, including your own, can be very hard. Remember, it is OK to use your family's strengths and ask for help when you need it. Sometimes, you may need help from family members outside your home,

friends and **mental health professionals** to keep your family together. That's OK, too.

Try to set aside time so everyone can have their own "time for me." For the adults in the house, this may mean time away from the children. Time to take a nap, read, or go for a walk. For the children, it can be time with a parent, grandparent, or a friend. Spend time with each child doing something special. These activities do not have to take long. Try an hour or 2 once a month to start. Do not be afraid to ask for help with child care, transportation, or other things that might get in the way of finding each person's "time for me."

Set aside special time for everyone in the family, including yourself.

What if I need a break?

The demands of caring for a child with a life-long health condition may feel like too much at times. It is important for caregivers to take a break when the stress level gets high. If your family or friends offer to help, take it! Ask them to help you with chores, or sit with your children while you go for a walk, visit with friends, or shop. If you need a break do not be afraid to tell your **case manager**. He/she can help you plan some time off.

Your case manager can help you plan time to take a break.

Respite programs

Respite (res' pit) programs provide child care for short periods of time so caregivers can go to the doctor or simply take a break. Respite can be arranged for a planned stay, such as over a

Respite programs can let you take time for yourself.

weekend, or for longer periods, if needed. There are respite programs around the state. Some of these programs also have medical staff to give your child his/her medicines. Your doctor or **case manager** can help you get respite care for your child.

Ask your case manager for a list of summer camps for your child and family.

Special summer camps for children with HIV

There are special summer camps that can give children with **HIV** a vacation and take care of their medical needs. This also gives parents and caregivers some time off, too. Some free overnight camps have services for older children and adolescents with HIV. All of these camps can provide the medical care and treatment the children need. There are day camps for the family, and some for children and adolescents only. Be sure to apply for camp early in the spring because camp lists fill quickly. Ask your **case manager** to help you find a summer camp and sign up your child or your family.

(See **Living with HIV**, Can my child go to camp or stay overnight with a friend? page 5–29.)

There are many programs to help you and your family.

What kind of services can I get for my family?

There are many programs to help you and your family. Your family may need one or more of the following services:

- assistance to buy food and clothing for your family.
- affordable housing.

- help with the rent.
- learning how to use the health care system.
- free or low-cost doctor-ordered medicines.
- counseling, or help in finding support groups and **respite** care.
- legal services.

Who can help me get services my family and I need?

Your **case manager** works closely with health and social service providers who take care of your child. He/she can also help you find services your child and family need to stay healthy.

If you do not have a **case manager**, ask your child's doctor or nurse to help you get a case manager. You can also get a case manager at medical facilities and community-based programs.

Your case manager can help you find the services you need.

Special Note for Foster Parents:

Call your caseworker for any services you or your foster child may need.

There are programs that can help with medical care and medicine expenses for your family.

Your case manager can help you find out if you can get Medicaid.

How can I get help to pay for medical care and medicine?

If you do not have health insurance, there are programs that can help with medical care and medicine expenses for your family.

Medicaid

Medicaid pays for:

- most medical visits.
- medicine.
- transportation to medical and mental health visits.
- special equipment such as wheel chairs or hospital beds.

Medicaid also pays for visiting nurse services if your child must have special nursing care at home. If needed, your child's personal care, as well as homemaking and home attendant services may also be covered. Your **case manager** can help you find out if you can get Medicaid.

Special Note for Foster Parents:

Your caseworker is responsible for making sure that your foster child has health care coverage in place.

ADAP (AIDS Drug Assistance Program)

Some people who do not have insurance may not qualify for **Medicaid** because their income is too high. **ADAP** and **ADAP Plus** provide insurance coverage for medical care and medicines for children and adults with **HIV** who are not covered by Medicaid. The program covers:

- doctor visits.
- **HIV** medicines ordered by a doctor.
- lab tests.
- emergency care.
- home care.

The program does not cover the cost of hospital care. **ADAP** and **ADAP Plus** programs are available through the **New York State Department of Health, AIDS Institute**. For information, ask your **case manager** or call:



ADAP and ADAP Plus
1-800-542-2437

Child Health Plus

New York State has a health insurance plan for children, called **Child Health Plus**. This plan covers children under age 19 who have no health insurance and do not qualify for **Medicaid**. Child Health Plus pays for most of your child's health care needs, including:

- doctor visits.
- dental care.

- **X-rays** and lab tests.
- emergency care.
- medicines.
- hospital care.
- short term treatment for substance abuse and mental health care.

Even if you are working, your children may be eligible for **Child Health Plus**. For information on how to apply, ask your **case manager** or call:



Child Health Plus
1-800-FOR-KIDS (1-800-367-5437)

Contact your case manager or Local Department of Social Services to apply for Family Health Plus.

Family Health Plus

New York State has a health insurance program for people between the ages of 19 and 64, called **Family Health Plus**. Family Health Plus is a free program for adults who do not have health insurance and do not qualify for **Medicaid**. Family Health Plus is provided through managed care plans in your area. Services include:

- doctor visits.
- hospitalization.
- doctor-ordered medicines and other services.

To apply for **Family Health Plus**, ask your **case manager** or call your **Local Department of Social Services**.

(See **More Information: Telephone Numbers**, page 11–2.)

Clinical trials

Clinical trials are research programs that test different kinds of medicines. **HIV** medicines are free if your child qualifies for a clinical trial. If your child qualifies, you must agree to have your child follow the clinical trial rules. These rules will include how much medicine to give your child and how often your child needs to visit the doctor. If your child is in a clinical trial, you have the right to stop giving the medicine if you think it is not helping your child. For more information, ask your **case manager**, or call:



HIV clinical trials hotline
1-800-TRIALS-A (1-800-874-2572)

Special Note for Foster Parents:

You cannot give permission for your foster child to join a **clinical trial**. Call your caseworker if you think your foster child may benefit from a clinical trial.

Transportation

There is help to pay for public transportation or to arrange ambulette or taxi service when your child has medical visits. **Medicaid** will pay for many transportation costs when the transportation is arranged through the hospital or clinic. Some programs in New York City provide metro-cards or tokens. Organizations such as Volunteers of America and the American Red Cross have special transportation programs for people with **HIV**. Talk to your **case manager** about your transportation needs.

Talk to your case manager if you need transportation to get your child to doctor or clinic visits.

Some programs provide services to help you care for your family.

What if I can no longer care for my family?

Sometimes, a caregiver may become too ill to care for a child. Or, a child may have severe behavior problems that cause too much stress for the caregiver and other family members. If you feel like you need help caring for your family, help is available.

In New York City, the **Administration for Children's Services (ACS)** has programs to help keep families together and to prevent the placement of a child in foster care. The **Preventive Service Division** can help with homemaking, child care and supervision, and behavior management. They can also help families get to needed medical and non-medical visits. All **Local Departments of Social Services** have preventive services programs.



Call your Local Department of Social Services to see if you qualify.

(See **More Information: Telephone Numbers**, page 11–6.)

A child may need to stay in a medical facility or foster home for a short time.

You can also ask your doctor or **case manager** how you can get these services.

Sometimes, a child may need to be placed outside of his/her home. This may happen when the child or a family member needs **psychiatric** (sī kē at' rik) care, or the caregiver is very sick or dies. If a child cannot stay in his/her home, he/she may need to stay in a medical facility or in a foster care placement for a short time.

There are legal service programs that help caregivers with **HIV** plan for their children's future. These programs help caregivers choose a family member or friend who will become the **guardian** or **standby guardian**. A guardian is a person who the court sees as being responsible for the care of a child. A standby guardian may also be appointed for a short time. For example, a standby guardian may step in if the caregiver is hospitalized or too sick to take care of the children.

(See **Legal Issues**, Why is it important to plan for my children's future? page 10–11 and How do I plan for my children's future? page 10–12.)

Caregivers need
to plan for their
children's future.

Notes

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